Health Services Management Research **14, 55–61**

HIV/AIDS challenges the normative model of healthcare delivery in Canada

P. Tsasis

McGill University Health Centre, Quebec, Canada

With advances in therapeutics, effective therapy for human immunodeficiency virus (HIV) has shifted the focus of HIV care from an acute illness to a chronic disease requiring the services of several disciplines in a primary care setting. This article describes a collaborative model in the delivery of HIV care for HIV-infected individuals who remain fragile, both physically and psychosocially.

Introduction

With the use of highly active antiretroviral therapy (HAART),the focus of HIV care over the past several years has shifted from what was once thought of as acute and often terminal to that requiring an array of disciplines and resources in the primary care setting (Goldbaum and Wood, 1999; Myers, 1998). As the HIV/acquired immunodeficiency syndrome (AIDS) care paradigm shifts from acute illness to a chronic disease, the complexity of the disease calls for integrated services within the primary care delivery model to help contain costs and improve patient adherence to therapy (Davis, 1999).

The provision of comprehensive healthcare for HIV-infected individuals who remain fragile, both physically and psychosocially with an ongoing need for treatment and social-service support is greatly complicated by the Canadian healthcare system. The system, historically, has been oriented to short-term acute care, and not to the ongoing need of monitoring the patient's current state of health while keeping in focus the patient's total disease course. Traditionally, the Canadian healthcare delivery system has primarily focused on acute-care hospitalization, rather than continuity of care (Health and Welfare Canada, 1993). In fact, the Canadian healthcare system continues to struggle to deal with illness as a series of events, rather than providing care across the disease continuum. This healthcare paradigm focuses on various healthcare specialties treating the illness rather than the disease itself. Consequently, this paradigm has resulted in a swelling incompatibility between servicing the healthcare needs of patient populations and the existing system of services aimed to attend to and treat those needs. The imbalance created by this incompatibility between community healthcare needs and the system itself does not allow for optimal conditions for service delivery. In fact, it is the major cause behind many of the difficulties of the Canadian healthcare delivery system, including misallocation of resources (Weatherill, 1992).

In essence, redefining healthcare services from the perspective of patient needs is imperative, as it establishes conceptual schemes that are not restricted to the implicit assumptions which have traditionally marked the Canadian healthcare system. Unquestionably, relatively

Peter Tsasis MBA, CHE, is a consultant in the Canadian healthcare system.
Correspondence to: 31 Succursale Beaubien, Montreal, Quebec H2G 3C8, Canada.

little research exists on the ideal mix, organization or orientation of providers to effectively satisfy the needs of the HIV patient population. This article primarily focuses on this difficult challenge.

The primary care encounter

With the expansion of testing efforts, the number of HIV-infected individuals who seek medical attention in the asymptomatic stage of the disease is steadily increasing (Rachlis and Zarowny, 1998). These individuals must follow a vigorous treatment plan, with initiation of HAART at the onset of the condition. HAART, together with prophylactic treatment of opportunistic infections and heedful follow-up, has been shown to extend survival rates in individuals afflicted with the disease (Rachlis and Zarowny, 1998). As a result, HIV infection has become a chronic disease that progresses over time and at a rate that is different for every infected individual (Rachlis and Zarowny, 1998). However, unlike chronic care patients, HIV-infected individuals fluctuate unpredictably between different levels of care (Levine, 1990). Hence, over a short period of time, HIV-infected patients may see a series of different healthcare providers in various settings (i.e. the outpatient clinic, hospital, and community care).

Under these various settings, fragmentation of care becomes a factor with which the patient must contend, and the overall quality of care received may be more determined by the resourcefulness of the patient than the success of the system. The challenge, then, is to ensure continuous care for HIV-infected individuals who enter various healthcare settings and progress through the system. In addition, medical care requirements which call for one to cope with symptoms, treatments and complications, along with complex issues involving loss of financial security, loss of family and other significant relationships, coupled with the psychological implications related to HIV, require thoughtful, comprehensive and multidisciplinary interventions. Moreover, given the increased awareness and sensitization to AIDS, stigma still often accompanies diagnosis and as a result, patient populations infected with the disease necessarily require the fulfillment of social and psychological needs (Dilley *et al.*, 1985). These patients are expected to follow an aggressive treatment regimen, and, more often than not, they do not have coordinated support systems established to deal with the varied emotional and financial hardships they often encounter (Cleary *et al.*, 1993) over and above the symptoms and medication side-effects they already endure.

Owing to the nature of the disease, HIV/AIDS patients clearly need a broad-based array of outpatient services and settings for the management of their medical and psychosocial problems, as well as for their support needs (Davis, 1999). Hence, treating HIV/AIDS patients necessitates continuity of care, compassion and comprehensiveness. For HIV service delivery, there is a need for *continuity* in the provision of care in which a provider–patient relationship develops (Ferrell and Neil-Page, 1993). The concept of ‘provider’ is not limited to denote an individual primary-care physician, it also can include a *team* of healthcare practitioners from varied disciplines taking a multidisciplinary approach to HIV medical service delivery (Rogers and Curtis, 1980). Adequate communication between various healthcare practitioners and the patient, through multiple contacts, over time, and often for a multitude of problems, in several settings, can ensure continuity of care with less fragmentation between services. *Comprehensiveness* arises from the willingness and ability of the healthcare provider(s) to handle the bulk of health problems that arise in the patient population served (Starr *et al.*, 1979).

The current trend of developing managed-care networks through the enhancement of primary-care services for HIV-infected persons, and a need to coordinate services and care for them through collaborative efforts, are associated with the steadfast increase in outpatient HIV care (Kirton *et al.*, 1999). As a result, some hospital-based outpatient clinics have integrated the care of patients with HIV into general medicine outpatient practices (Makadon *et al.*, 1990). Other hospitals have created ambulatory HIV clinics, which care for patients with HIV infection by providing specialized medical care using a multidisciplinary team approach (Volberding, 1988). ‘Case management’ — as it is commonly referred to — has also been implemented as a vehicle for overcoming system fragmentation and for facilitating optimal service delivery (Aseltyne *et al.*, 1995).

Many definitions of case management for people with HIV/AIDS have been advanced in the literature. A significant number of these emphasize the role of the case manager as a 'navigator' who steers patients through the complexity of the healthcare system and guides them to appropriate and tailored services that fit their personal needs (Benjamin, 1988; Morrison, 1990). Yet, an effective and expansive HIV case-management system requires not only navigating the patient through the system; it also requires linking medical treatment, psychosocial support and physical rehabilitation to enable the formulation of biopsychosocial treatment schemes to improve the patient's overall well-being (Kocurek, 1996).

The benefit of HIV case-management system first became evident about a decade ago, when a managed-care network of community-based health and social services was developed. This subsequently resulted in both the improvement of patient and provider satisfaction with care delivered, and a decrease in the length of hospital stay for HIV/AIDS patients (Arne and Hughes, 1987). This framework was developed at the University of California, San Francisco, and became known as the 'San Francisco model'. It is a classic example of a successful case-managed continuum-of-care model that emphasizes outpatient services in HIV care.

Specifically, the San Francisco model provides comprehensive care through the coordination of HIV/AIDS services in various healthcare settings. Essentially, through a managed-care network, the services provided range from community-based home care, long-term care, mental healthcare and hospice care. San Francisco General Hospital, which is part of the network, also provides an acute-care inpatient unit that is integrated within an ambulatory care setting, comprising an HIV-specialized multidisciplinary team of oncologists, infectious disease specialists, psychiatrists, nurses and social workers. Moreover, community-based organizations work in tandem within the network in order to provide education and prevention programmes for those most prone to participate in high-risk behaviour. In addition, service organizations provide support service programmes that give quotidian assistance to HIV patients, such as transportation and housing, assistance with daily living activities, along with emotional counselling to patients, partners and family members. Emergency and long-term residential facilities for those infected with HIV who no longer can afford housing are also available, along with access to food banks and transportation to outpatient clinical services.

The success of the San Francisco model is primarily due to the strong collaborative and formalized relationships that have been developed between public and private community-based healthcare providers, who, in partnership with the mutidisciplinary and HIV-specialized ambulatory centre at San Francisco General Hospital, provide case-managed care to HIV patients. Such a centralized and integrated model of service delivery facilitates case management in linking the numerous medical and psychosocial needs of HIV/AIDS patients with the appropriate level of care along the healthcare continuum.

The San Francisco model has been adopted in Canada in densely populated communities where there are large university-based hospitals with HIV-specialized ambulatory centres (e.g. Vancouver, Toronto and Montreal). However, the community support system for HIV/AIDS patients in Canadian cities is less well developed than in California. Moreover, despite a significant number of providers and outpatient settings being simultaneously involved in the care of HIV-infected patients, poor coordination and communication among primary-care physicians, HIV-infection specialists, HIV ambulatory service providers and home-care providers has resulted in a fragmented AIDS healthcare network with an inconsistent focus on patient needs. Additionally, even though information is gathered by various providers who attend to the HIV patient in various settings, often there is no consistent effort made to compile this information into a comprehensive database that addresses the patient's overall care needs.

Challenges for primary care

When treating HIV patients, it is possible to lose sight of the whole person and become focused and distracted by the multitude of factors that go into treating such an individual. Service delivery models for the constantly changing field of HIV care must recognise and address the multisystem nature of the disease, the intensity and complexity of therapy, and the profound psychosocial problems that arise in the therapeutic setting. For instance, the drug regimen plans to which this patient population must adhere complicate patient care for HIV-infected individuals. Medication regimens have complex dosing profiles and can have potential side-effects. This, along with the psychosocial aspect of having acquired such a devastating disease, can be overwhelming and dispiriting for the patient and can lead to depression (Myers, 1998).

Concomitant with the notion that AIDS is a chronic disease that progressively advances with frequent and unpredictable medical exigencies, it may be argued that different healthcare settings are suitable for a particular patient at different times (Morrison, 1990; 1991). The most appropriate healthcare setting for any individual at any one time will depend on the particular circumstances of the individual's medical and psychosocial needs and on the patient's support network. The ability to meet the patient's needs depends on the healthcare provider's scope of HIV care, and his/her capacity to integrate available community resources and services. Essentially, this may be seen as a major challenge in the normative context of the Canadian healthcare delivery system since collaboration — defined as the process of joint decision-making across professional boundaries of healthcare settings — is episodic and discontinuous (Weatherill, 1992). Additionally, the limited focus in defining and evaluating HIV case management within a medical model has been a major dilemma in attempts to implement case management in AIDS service organizations. Emphasis on a medical model, as opposed to a socio-medical model of care provision has created differences in perspective between medical and social services-related disciplines, which has impeded communication. Therefore, for the implementation of case management in HIV/AIDS service organizations, there is a real need for a model that addresses the medical complexities of HIV within the context of the patient's psychosocial reality.

Clearly, there are conceptual and clinical challenges in matching the many chronic, medical and psychosocial needs of HIV patients with the appropriate level of care along any healthcare continuum. Focusing on the patient's needs, however, centres one's efforts away from traditional medical specialties where health professionals work separately in various organizations, and towards multidisciplinary professional collaboration across organizational boundaries into community networks. This multidisciplinary approach to HIV care must be provided at the time of diagnosis and initial treatment, as well as during the disease continuum, in order to enable the patient to achieve physical comfort and emotional ease.

Primary-care physicians must also provide a holistic perspective in meeting the patient's health needs; however, treating and caring for HIV patients poses a difficult challenge (Lewis and Donohoe, 2000). Primary-care physicians who attempt to care for such patients often face a spectrum of disease conditions that are complex, difficult to manage, and require familiarity with deciphering a rapidly expanding body of medical knowledge and a vast array of new and complex therapies (Soloway, 1997). In addition, primary-care physicians often lack the necessary expertise to provide the complex care needed by HIV-infected patients who have a multiplicity of diseases, none of which are categorized as primary-care diseases (Lewis and Donohoe, 2000).

In essence, the San Francisco model owes its success to the collaboration and integration of professional activity that revolves around locally accessible primary care. This is supported by secondary and tertiary activity that is all-embracing and responsive to the biopsychosocial needs of the HIV/AIDS patient, and supplemented with the continuous expertise of HIV care specialists. Essentially, the cooperative nature of the system ensures better continuity of care for patients, and improves ease of care for healthcare providers and overall quality of care for the patient. Hence, the San Francisco model has much from which other systems — particularly the Canadian healthcare system — can learn and adopt.

Collaborative practice in the primary care setting

Given the constraints of fragmented service delivery associated with HIV care in Canada, integration and coordination of services, as well as continuity of care, may be successfully achieved through a strategy of 'shared care': this is defined as the joint contemporaneous responsibility of generalists and specialists in the planned delivery of care for the patient (Pritchard and Hughes, 1995). The concept of shared care provides a useful framework for determining the best mix of care from healthcare providers with generalized and specialized expertise in HIV care, and it also provides a link between primary care and the rest of the healthcare system. The optimal mix of primary and specialized care is not yet clear for patients infected with HIV, but it is likely to depend on the patients' needs and on the primary-care physician's ability to meet those needs. Undoubtedly, the patient will always benefit from an ongoing relationship with a primary-care physician, and the primary-care physician's traditional role as a patient advocate should be part of any HIV model of care. However, patient care also requires the involvement of healthcare professionals with specialized expertise during the course of the disease.

This philosophy of care is embedded in a multidisciplinary approach to patient care. Referral and consultation may be appropriate in the treatment of illness for which narrowly defined expertise is needed for a limited time — such as an acute surgical intervention. HIV management, however, requires an ongoing relationship between the patient, primary-care physician and specialists from the medical and psychosocial domains because the disease is complex and chronic. As a result, shared care requires an exchange of information that is more sophisticated than the traditional referral letter and reply. It involves a diagnosis-oriented information system where patient data are gathered by various practitioners as they evaluate the patient, and this information can then be made accessible to all those involved in the patient's care.

Recently, shared-care schemes have been promoted as a means of integrating knowledge and skills of specialists and primary-care practitioners, particularly for chronic disease management (for example, diabetes [Schroder, 1995] and asthma [Van Damme *et al.*, 1994]). This also could be done with HIV care, since the HIV specialist or multidisciplinary team of specialists have more technical knowledge, while the general practitioner and patient have knowledge that is unique and important for defining the context and appropriateness of shared care. In this model, everyone works together to provide structured care, with an emphasis on systematic monitoring of the patient over a period of years, often within a framework of jointly agreed-upon guidelines or protocols.

As HIV expands more and more into the chronic disease spectrum, timeliness of intervention has become increasingly important, as disease manifestations are likely to be much more severe for HIV-infected individuals (Myers, 1998). As a result, multidisciplinary care must be provided as a comprehensive process of continuing care, which may be accessed at any point in the disease continuum. Additionally, behavioural, psychosocial and rehabilitation issues must be emphasized as an ongoing process of comprehensive care for the patient. Even though continuity of care delivered within a system of interdependent relationships among practitioners has been shown to be effective and cost-efficient (Baradell, 1994), few academic papers have been published to date *vis-à-vis* the general principles and practice of shared care in the care and treatment of HIV. However, with the shift of HIV care toward primary and community care, it is important that such a shift be accompanied by a corresponding shift of knowledge, skill, technology and resources. Shared-care frameworks can provide a substantial transfer of knowledge and skill across professional boundaries from a multiplicity of HIV/AIDS care professionals towards the management of the individual patient's needs.

Theoretically, the underpinning scheme for achieving integration of care can comprise a transitory multidisciplinary professional team, adjusted in composition and leadership to the needs of the individual patient within a shared-care plan. That is, the team interchanges personnel and responsibilities on clinical decision-making as it addresses the *ad hoc* problems posed by the individual patient and his/her primary-care physician. Team composition can change routinely even for the same patient, as the number, variety and intensity of needs change. The HIV medical care specialists in the team may provide leadership when the situation requires knowledge of efficacy of new treatment regimens, and can work with the other team members to develop a healthcare plan to meet the short- and long-term needs of the patient. Clearly, such a shared-care scheme requires a high degree of communication between clinicians and requires that the clinical healthcare plan be explicit and available to all healthcare providers in the team. Ongoing assessment is also important in determining a patient's changing needs. The system used to do this must be flexible and suitable for multidisciplinary use. By permanently recording successive, continuing assessments, patient care needs can be highlighted and used to adjust the skill and knowledge mix of the multidisciplinary team to meet the patient's changing needs more effectively. Future developments in new technologies for distributing 'electronic health records' will ensure that this model of care can be supported adequately.

When the patient's condition requires psychosocial support, the team may, for a period of time, be under the leadership of a social care professional. Data on observations made by other healthcare professionals (i.e. a nurse, dietician, physician, physiotherapist, and so on) can be transmitted to the team on a continuous basis, through an integrated computerized information system, with every practitioner on the team able to access the data routinely. The comprehensive clinical health record can comprise data from primary-care clinicians, medical specialists, social-care professionals, nurses, physiotherapists, pharmacologists, laboratory service personnel, and radiology and diagnostic service personnel. As a result, the team can assess adequately and collaboratively the data and decide upon the issues and how to best work with the patient and the patient's support network for optimal care. Essentially, medical and social primary-care providers can achieve this most effectively, with medical specialists having joint responsibility for the treatment and care of the patient. Moreover, by documenting all patient information available, the comprehensive clinical health record can be used to determine the patient's needs and resources at any given time, and to integrate responsibilities of the multidisciplinary process for providing quality care across the healthcare continuum. This system contrasts with the current system of referral between primary-care providers and specialists, where, often, responsibility for the treatment of the patient is passed over from one healthcare provider to another. The HIV patient care team also can coordinate patient transfer among institutional care facilities, thus creating an interface so that patients are able to move easily from one level of institutional care to another, depending on their level of functional disability and symptom severity. For instance, if the patient suffers a minor incapacity, care can be provided in the community through rehabilitative services. That is, the patient care team would see the patient regularly but would rely heavily upon community services and the patient's support network to carry major responsibilities.

Conclusion

With combination therapy shifting the focus of care for HIV-infected individuals to the outpatient setting, the rationality of shared care has the potential capacity to provide access to secondary and tertiary care that is guided by the primary-care physician. The new vision herein, which proposes patient-centred care across a continuum of need within a shared-care scheme, ultimately leaves many questions unanswered, which can lead to a rich research agenda. For instance, what healthcare system linkages are required for the creation of an ongoing multidisciplinary forum? What systematic context supports and contributes to creating collaborative relationships? What incentives are necessary to stimulate shared care? Where will the primary healthcare transitory teams be located? What is the best composition for a given team so as to enable it to provide treatment and care to HIV patients? Who should lead the team and under what conditions? When should the leadership change? And how? How should that decision be made? How do we facilitate the input of all team members? What documentation practices will we use to reflect a collaborative interdisciplinary process? How do we measure the team's effectiveness? How do we incorporate the knowledge gained from research into measurable improvements in the processes and outcomes of patient care? And how do we guarantee patient confidentiality?

Overall, efforts toward multidisciplinary professional collaboration must build upon the strengths of team coordination, professional expertise, and patient and primary-care physician participation. Moving away from the old paradigm to create an integrated approach to patient care is not without challenges. Undoubtedly, research is required on the impact of new organizational and constructural relationships for groups of professionals, on methods of shared decision-making, and on ways of promoting understanding of roles between practitioners in medical and social care. In addition, questions about autonomy, decision-making and professional boundaries further necessitate examination.

Unquestionably, in developing a commitment to shared care, healthcare providers must define the mix and process of care that will optimize patient outcomes on the basis of the patient's needs and on their ability to meet those needs.

In formulating such an approach, the use of a multidisciplinary team increases the accessibility of the healthcare provider to the patient and brings a variety of unique skills from the medical and psychosocial fields, which can be applied in the treatment and care of patients infected with HIV.

Ultimately, healthcare in Canada will undergo significant transformation. Even though one may deduce that the impetus for the change is fundamentally financial in nature, financial viability will depend on successful implementation of coordinated and multidisciplinary models of care across a full continuum of care. In essence, chronic disease management of HIV care plays a critical role, and significantly challenges healthcare providers to formalize shared-care responsibilities in the Canadian healthcare system.

References

Arne, P. S. and Hughes, R. G. Local policy responses to the AIDS epidemic: New York and San Francisco. *New York State Journal of Medicine* 1987; 87: 264–71

Aseltyne, J. W., Cloutier, M. and Smith, D. M. HIV disease and managed care: an overview. *Journal of Acquired Immune Deficiency Syndrome and Human Retrovirology* 1995; 8(suppl 1): S11–22

Baradell, J. G. Cost-effectiveness and quality of care provided by clinical nurse specialists. *Journal of Psychosocial Nursing and Mental Health Services* 1994; 32: 21–4

Benjamin, A. E., Lee, R. P. and Solkowitz, S. N. Case management of persons with acquired immunodeficiency syndrome in San Francisco. *Healthcare Financing Review* 1988; annual suppl: 69–74

Cleary, P. D., Fowler, F. J., Weissman, J. *et al*. Health related quality of life in persons with acquired immune deficiency syndrome. *Medical Care* 1993; 31: 569–80

Davis, S. The role of advanced practice in today's infectious diseases. *Critical Care Nursing Quarterly* 1999; 21: 22–30

Dilley, J. W., Ochitill, H. N., Perl, M. and Volberding, P. A. Findings in psychiatric consultations with patients with acquired immune-deficiency syndrome. *American Journal of Psychiatry* 1985; 142: 82–6

Ferrell, B. and O'Neill-Page, E. Continuity of care. In: Groenwald, S., Froggre, M. H., Goodman, M., Yarbro, C. H. (eds.) *Cancer Nursing: Principles and Practice*. Boston: Jones and Bartlett Publishers, 1993

Goldbaum, G. M. and Wood, R. W. Improved therapies for HIV infection and AIDS implications for primary care. *Journal of the American Board of Family Practice* 1999; 21: 97–9

Health and Welfare Canada. *Planning for Health. Toward Informed Decision Making: Summary of Literature Review and a Proposed Evaluation Framework on Emerging Trends in the Organization and Delivery of Healthcare Services*. Government publication. Ottawa, 1993

Kirton, C, Ferri, R. and Eleftherakis, V. Primary care and case management of persons with HIV/AIDS. *Nursing Clinics of North America* 1999; 34: 71–94

Kocurek, K. Primary care of the HIV patient: standard practice and new developments in the era of managed care. *Medical Clinics of North America* 1996; 80: 375–410

Levine, C. In and out of the hospital. In: Gostin, L. O. (ed.) *AIDS and the Healthcare System*. New Haven, CT: Yale University Press, 1990: 45–61

Lewis, C. and Donohoe, T. Changing sources of care for HIV infection in California. *AIDS Education and Prevention* 2000; 12: 15–20

Makadon, H., Delbanco, S. and Delbanco, T. Caring for people with AIDS and HIV infection in hospital-based primary care practice. *Journal of General Internal Medicine* 1990; 5: 446–50

Morrison, C. Case management and the determination of appropriate care settings for persons living with AIDS. In: Heussner, R., Hoffman, W. (eds.) *Community-Based Care of Persons with AIDS: Developing a Research Agenda.* Minneapolis: Department of Health and Human Services, 1990: 75–82

Morrison, C. Creating and managing a therapeutic environment: institutional settings. In: Durham, J. and Cohen, F. (eds.) *The Person with AIDS*. New York: Springer Pub. Co., 1991: 228–44

Myers, R. Outpatient management of HIV-infected adults: the varied challenges for primary care. *Postgraduate Medicine* 1998; 103: 219–28

Pritchard, P. and Hughes, J. *Shared Care: Future Imperative*. The Nuffield Provincial Hospital Trust. London: Royal Society of Medicine Press, 1995

Rachlis, R. A. and Zarowny, D. P. Guidelines for antiretroviral therapy for HIV infection. *Canadian Medical Association Journal* 1998; 158: 496–505

Rogers, J. and Curtis, P. The concept and measurement of continuity in primary care. *American Journal of Public Health* 1980; 70: 122–6

Schroder, F. Shared care in diabetes. *BMJ* 1995; 10: 142–3

Soloway, B. Primary care and speciality care. *AIDS Clinical Care* 1997; 9: 37–9

Starr, G. C., Norris, R., Patil, K. D. and Young, P. R. What is comprehensive healthcare? *Journal of Family Practice* 1979; 8: 161–6

Van Damme, R., Drummond, N., Beattie, J. and Douglas, G. Integrated care for patients with asthma: view of general practitioners. *British Journal of General Practice* 1994; 44: 9–13

Volberding, P. Caring for the patient with AIDS: an integrated approach. *Infectious Disease Clinics of North America* 1988; 2: 543–50

Weatherill, J. Beyond four walls: ideas and application on regional planning of healthcare services. *Healthcare Management Forum* 1992; 5: 48–53